

Letter to Dr. Lerner from a Concerned Illinois Resident
August 27, 2005

From: Najma Alkis [mailto:najmahu@yahoo.com]
Sent: Saturday, August 27, 2005 11:35 AM
To: Wayne Lerner
Subject: Adequate Health Care Task Force

Dear Mr. Lerner,

Congratulations on being appointed for the Adequate Health Care Task Force. I was sure to write and commend Governor Blagojevich for the budgeting of \$1 million for the implementation of the Health Care Justice Act. I support the Adequate Health Care Task Force's plan to provide all Illinois residents with access to a full-range of preventive, acute, and long-term health care.

I would like to provide you, as a member of the Adequate Health Care Task Force, with some first-hand "uninsured patient" experiences that may help in creating a comprehensive health care access plan for Illinois that is based on real experiences of real people in the present times.

I was a vital, healthy, active community member. Now I am a 40 year old woman seriously ill with a chronic and long term illness since April 2002. It is called mycobacterium avium complex pulmonary disease. Normally people with HIV get it, yet I am HIV negative. I know first hand that physicians made treatment and diagnostic decisions based on my lack of insurance rather than true need. As recently as two months ago a physician, a specialist, reversed a decision to perform crucial tests based on my lack of insurance.

I fell ill so quickly and acutely, that I was forced to close my business, get on emergency food stamps, and move into a housing arrangement where I could receive care while bedridden. No hospital would keep me and assess me beyond the ER. My small savings evaporated within the first months.

I applied for Medicaid at the onset, when my illness was acute, and was denied. I later reapplied and was denied again. Three years later, and now in a wheelchair, I am applying again. I use a rural health clinic who bases payment on income; in my case I am eligible for a discount. I was placed on patient assistance programs for my two years of chemotherapy treatment. I cannot get the two most expensive medications from pharmaceutical company programs. I take eight medications. The most expensive are the antibiotics, \$400 a month each. These aren't symptom reducing medications, they are the cure. They are required for two to three years as this bacterium is extremely difficult to eradicate, characterized by multiple antibiotic resistances. The bacterium is a ubiquitous air and water bacterium that normally causes no illness in humans.

I would like to communicate my story to the appointed Adequate Health Care Task Force, so that they can take some aspects of my experience into consideration. I often see comments written such as:

Dr. Eric E. Whitaker, state public health director stated that, "Those who are uninsured usually lack the resources to pay for needed care and are likely to delay seeking care until their health has deteriorated and the treatments required are more complicated and more costly." <http://www.idph.state.il.us/public/press05/7.31.05.htm>

There are also those of us who do not delay needed care. We apply for Medicaid, needing medical coverage, and get denied. We are working class citizens who, when we lose our job due to illness, become poor. (I was a locally reputable clinical massage therapist in private practice, often serving survivors of sexual and physical trauma. I have a background in medical social work). Being labeled by a billing department as a "self-pay" with low income or no income can produce the same results as delayed treatment. I have had physicians decide not to perform necessary tests and procedures, or reverse their decisions on tests they initially ordered, based on my lack of insurance. Inadequate testing can be just as responsible for progressively poorer health and ultimately, as in my case, the development over time of disability due to worsening illness that was inappropriately treated in its earlier phases.

In response to another statement from the same memo, from Governor Blagojevich, personal bankruptcy is only one burden. "In addition to health-related impacts, high levels of uninsured impose serious economic burdens. For individuals, inadequate health insurance coverage results in medical debt, a frequent and increasing cause for personal bankruptcies. For providers, treatments administered to the uninsured result in significant financial losses due to uncompensated care."

Also include the economic burden to Federal social security disability by patients who have, like me, become disabled a result of inadequate healthcare. Had proper testing been performed and a diagnosis revealed, then appropriate treatment could have begun promptly three years ago and I would not be disabled today. I needed a test to determine the proper medications to apply in my case. Without the results, I was asked to take medications that were shown to be ineffective in such a test. This has been repeated. Just two months ago specialist at Washington University in St. Louis refused to order this test because of the cost, despite my status as pending Medicaid, despite our offer to pay for the test ourselves. As a result, she prescribed medications that were shown to be ineffective when the test came back. (My husband ordered the test independently and paid for it himself). The nurse literally gave me the number of the state lab and said we were on our own. We end up taking healthcare in our own hands in attempt to get the answers required for appropriate treatment.

I have been administered the wrong medications by three different physicians. Remedy that by facilitating physician communication standards. My primary care physician was not even notified of positive test results indicating the disease. Not the state lab, nor the pulmonologist, nor the Jackson County Health Department notified my physician of the positive test results. Perhaps if I had insurance, I would be able to afford pulmonologists

and infectious disease specialists and not depend on a rural clinic doctor to manage this rare disease.

With all the discontinuity in care, I am now more ill than I ever should have been. Had the appropriate medical decisions been carried out in the initial stage of illness by the needed specialists through continuity of care, rather than the patchwork of care I have received the past three years, I would not have such disastrous health consequences.

I am appealing SSDI and pending Medicaid. If denied Medicaid, my recent hospital stay, visit to specialists and medications and equipment will be left unpaid. If denied, when I appeal, I will not have the same date of retroactive payment, thereby accruing more medical debt.

The Adequate Health Care Task Force needs to reexamine the Medicaid process. Acute illnesses that are not treated appropriately by those who seek prompt treatment will only add to the medical burden on the state later on when the Medicaid finally gets approved under extreme health circumstances and the patient is so critically ill that more advanced and complex care is required for a longer period of time.

The Adequate Health Care Task Force needs to put some medication programs in place that covers the gap where patient assistance programs leave off, particularly for long term therapies crucial to a cure. Most states have such programs, but Illinois has only programs for children, mothers and seniors. Attention to medication assistance programs for adults, our workforce, needs to be provided. Illinois has no such program.

The Adequate Health Care Task Force needs to assist and educate doctors on the ethical responsibility of the doctor toward the patient and accountability for inappropriately treating of uninsured patients. They need to be aware of screening patients for roadblocks to full recovery.

Overall, my case is an example of an average Illinois working class citizen that found no medical support system to assure appropriate treatment in the event of acute onset catastrophic illness. I hope my story has been helpful in shining the light on what real people in Illinois experience within the healthcare system.

Sincerely,

Lynn Waters
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